THE UNIVERSAL FELLOWSHIP OF METROPOLITAN COMMUNITY CHURCHES

ALERT

News from the UFMCC
on AIDS Legislation, Education, Research and Treatment.

JUNE, 1990
Editor: Rev. Dr. A. Stephen Pieters

BURUNDI FACES AIDS

by Frank Carothers
(reprinted with permission from the OPTIMIST, APLA Spring '90)

Burundi, sometimes described as the Switzerland of Africa is hard to spot. If you look on a map for Lake Tanganyika - one of the largest fresh-water lakes in the world - you'll find Burundi on its northeast shore, surrounded by Zaire, Tanzania and Rwanda. Burundi is where a buckle would be if Africa wore a belt around its constricted middle.

"Burundi is probably the most pristine place I've ever seen in my life. It is exquisitely beautiful," said AIDS Project Los Angeles Program Manager for Mental Health Services Sally Jue, who recently visited the country.

The land is hilly, lush and green. There's no pollution, and almost no industry - 93 percent of Burundi's work-force are in agriculture.

Automobiles are so few that there is not a single traffic signal in the entire country - not a one. A nation where people hail from hills rather than cities or villages, Burundi is a place where home mail delivery is unheard of.

"Burundi is unspoiled," said Jue. "Every afternoon, about five or six, herds of hippos come out to graze around Lake Tanganyika."

But beneath the calm, the fertility, the beauty of the country lies the ever-growing menace of AIDS.

Like the Central African nations that surround it, the tiny nation of Burundi is in the midst of an AIDS crisis.

According to the World Health Organization, as of last January, 2,355 cases of AIDS were reported in Burundi, a country which has one of the most densely packed populations on the continent, as well as one of the poorest, with an average per capita annual income of $273.

Burundi's AIDS case load is dwarfed by the 121,645 AIDS cases reported in the United States. In proportion to its resources, however, Burundi's AIDS crisis is more grievous than the pandemic here.

"Burundi has short, medium, and long range goals for dealing with the epidemic, and they are doing their best to implement those goals," said Jue. "In some ways," she continued, "Burundi is way ahead of the United States, in that their government actually has a national plan for dealing with AIDS. That's something this country has yet to get around to."

Last December the Burundi government requested that the AIDS Agency for International Development select a team of U.S. consultants to help them in their struggle with AIDS. Jue was part of that group.

Jue's many years of working with AIDS issues at APLA, her experience as a medical social worker, and her master's degree in social work were impressive qualifications for the appointment. Beyond those credentials, Jue also can read, write and speak in French, the language spoken by Burundi officials.

For two weeks, Jue worked with the Burundi National AIDS program, to help develop and implement an AIDS counseling training program for doctors and social workers. They trained 34 people from all over Burundi, as a part of a systematic plan the government is developing.

Some clinics of Burundi, according to Jue, report that nearly one-quarter of those tested for exposure to HIV are antibody-positive.

In the capital city of Bujumbura, 28 percent of all women in the hospitals were there for HIV-related reasons. A pediatrician in Jue's group reported that three out of five children she tested were positive.

"High Risk" groups are not defined in Burundi. The entire population is at risk. And although the infection was initially concentrated in Bujumbura, it has steadily and inexorably spread throughout the country, out into the rural areas.

"There are whole families that get infected and die," Jue said. One of the problems facing Burundi, she added, is that AIDS may mean that there will be "a whole generation of children without parents or other adults to raise them."

The stigma associated with AIDS is strong, Jue said. "Sometimes the family will bring the person to the hospital, and then leave them. They never come back."

In U.S. hospitals, Jue said, "you call the family on the phone, you send them a letter. But in a country where there's no home mail delivery, where there's a grass shack in the hills, where there's no address, and most

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people don't have phones - you have no way to track down the family."

Meals are not provided for patients in Burundi hospitals; families are expected to provide food. "If you're abandoned by your family, you don't eat," Jue said. "Sometimes the staff will feel sorry for people and they will pitch in and bring that person food sometimes. But, you know, as the epidemic grows, they can't do it for everybody."

The average American would find it hard to understand the depth of the AIDS crisis in Burundi, Jue said.

Americans take for granted the U.S. social welfare system, the experimental drugs available here, our elaborate support systems - the Buddy programs, the food banks, the whole range of services provided by APLA and thousands of other AIDS service providers.

None of that exists in Burundi. "They have no public assistance programs," Jue pointed out. "They have almost none of the medical treatments that we do. There is no AZT, no pentamidine, no ddI, no DHPG. They don't exist. They can't afford them."

"They have a high mortality rate due to poor medical care, anyway. Even before AIDS, the life expectancy was only 45 - you can imagine what HIV has done to the country."

In the face of such problems, what can be done?

Beyond helping to organize the AIDS counseling program, a major goal of the consultants was to help set up HIV medical teams in the hospitals. HIV hospital units are not possible; there are too many people in their hospitals with HIV. "A part of their interest is in what our experiences have been with such teams, and what suggestions we had for setting them up," Jue reported.

"Education," she added, "is paramount. It's really one of the very few weapons they have. But even there they have to do it differently. You can't use TV. A lot of people can't read - their literacy rate is well below 50 percent. If you're in the country you don't go to school. Most of the education has to be word of mouth. Health care providers are one of the key routes for getting information out to people. But that's a problem, too, because it's a culture where you don't talk openly about sex." Homosexuality, she observed, is never discussed openly.

"It's hard for them," Jue concluded. "But they're dealing with AIDS. They have some very intelligent and resourceful people who are working with far less than anything we've ever had to deal with. And we complain about what we don't have, in this country! It was hard to talk with them about our experiences. We have so much more than they could ever have. What could we talk about that was possible attainable for them, given their resources and their culture?

"One of the things this experience gave me is perspective. Nothing that we have is as bad as what these people have to deal with.

"Then I came back here and talked with the National AIDS Commission about what we need and what we're missing. And I though about that gap."

(Frank Carothers is an APLA volunteer)

LETTER FROM REV. ELDER TROY D. PERRY

Dear Sisters & Brother in Christ:

As you may know, several years ago I accepted an invitation to join the Board of Directors of the National Lesbian and Gay Health Foundation (NLGHF). The NLGHF has over a decade of experience working with health care providers and consumers in order to provide education and advocacy around issues of quality care for lesbians, gay men and people with AIDS.

Over the past several years, the NLGHF has published the Sourcebook on Lesbian and Gay Health Care, completed and published The Final Report of the National Lesbian Health Care Survey, and undertaken three annual national health conferences. I want to make you aware of a special opportunity in which I hope you will be able to participate. This summer from July 18-22, in Washington, DC, the Foundation will be hosting the Twelfth National/Third International Lesbian and Gay Health Conference and Eighth National AIDS Forum.

I want to encourage each and every one of you who can to participate in this event. In addition to the over 200 concurrent sessions dealing with a broad spectrum of issues such as mental health, AIDS medical concerns, substance abuse and recovery, lesbian health concerns, issues of special concern to people of color and youth, there will be special plenary sessions, day long institutes and several three hour evening seminars. One of the evening seminars concerns Spiritual Wholeness and Metropolitan Community Churches perspective over the last 21 years.

If you are able to do so, register and join me in Washington, DC for this important and far reaching conference. I look forward to seeing you there.

For information and to register contact: NLGHF, 1638 "R" Street, N.W., Suite 2, Washington, DC 20009; or call (202) 797-3708.

LABORATORY TEST SUGGESTS POSSIBLE DEMENTIA TREATMENT

(by John S. James; reprinted with permission from AIDS Treatment News, #101, 4/20/90)

A study published in Science (April 20) showed that in a laboratory test, rat brain cells were injured by very small amounts of gp120, a protein made by the AIDS virus. The cells could be protected by small concentrations (100nM) of nimodipine, a prescription drug used to reduce neurological damage in certain cases of bleeding in the brain. The concentrations effective in the laboratory test can be attained in patients.

In the laboratory study, gp120 appeared to harm nerve cells by causing them to absorb too much calcium - over 30 times the normal level. That is why nimodipine, a calcuim channel blocker, was tried in this test-tube study. The authors suggested more research to see if this drug might be useful in treating or preventing AIDS-related dementia or other neurological damage.

WHAT HAPPENS NEXT? Results from a laboratory study of rat brain cells cannot predict what will happen in patients. Even if the drug could work, no one knows the right dose. While nimodipine is fairly safe in its standard use (the most common side effect is decreased blood pressure), there is no information on its use by persons with AIDS, or on combining the drug with AZT or other treatments which would still be necessary, since nimodipine would have no effect on the HIV infection itself.

AIDS Treatment News called the senior researcher of this study, Stuart A. Lipton, M.D., a neurologist at Children's Hospital in Boston and at Harvard Medical School. He told us that he has a clinical trial ready to go; he is now talking with Miles Pharmaceutical, the company which owns the drug, seeking support for it. We mentioned that other funding might be found, but Dr. Lipton feels strongly that the company which owns the drug should pay for the study.

We called Miles Pharmaceutical and reached a spokesperson in the public relations office. He said that while Miles was ready to support pre-clinical and animal studies (he emphasized those words in our conversation), they wanted more information before trying it in patients for example, a test with another animal model. He mentioned that Miles had no experience with AIDS, but had been told that rats do not get the disease; scientific implications of that fact might be considered.

COMMENT: It became clear that here was another example of the kind of misunderstanding that repeatedly derails practical AIDS research, due to the lack of national leadership ready to move in an emergency. It is understandable that a pharmaceutical company unfamiliar with AIDS would want more than a study of rat cells in a laboratory dish before sponsoring a trial. And yet the drug is believed safe, and ultimately - no matter how much animal work is done - the only way to see if it works will be for patients to try it. Dr. Lipton wants a trial now so that people will not start using the drug on the basis of one laboratory study, in the absence of any human trial for its use in treating AIDS-related neurological damage. We sensed that the parties had been talking to each other for some time before the article was published; they seemed to have reached an impasse.

Since no one knows if the drug will work at all for AIDS-related dementia or other neurological problems, no one knows if it would only be preventive, or if it could reverse symptoms already present. Fortunately AZT can often reverse dementia, showing that the damage is not irreparable. If nimodipine can clearly improve patients' condition, then a clinical trial would be relatively easy; it could be conducted by a community-based trials organization, or by an individual physician. But if the drug could only prevent the problem and had to be given in advance, a clinical trial would be difficult to administer, because it would require many patients and a long time to obtain the required evidence.

If no trial happens soon - we especially need the easy trial, for treatment as opposed to prevention - it is inevitable that people will start trying the drug without waiting for a scientific study.

MY PROBLEMS WITH BORROWED TIME
(by Paul Monette)

(New York: Avon Books, 1988
Review by: Rev. Dr. Stephen Pieters)

I resisted reading Borrowed Time. I knew that Paul Monette grew up in the same town I did, went to the same schools, and that his lover, Roger, had AIDS at the same time I was sick with it, and took the same experimental drug, suramin, while living in the same city, Los Angeles and I knew that Roger died at the end of the book. So I'm coming at this review with a unique perspective: as someone who survived what Roger did not.

The book is beautifully written. Monette is obviously a gifted writer. It is tragic when a man loses the love of his life to a dreadful, premature, lingering death. It is compelling reading. I am sure this will go down among AIDS literature as a classic of the early years of the plague. It is an eloquent description of a devoted and gifted couple nobly battling AIDS among the upper class of gay white men in Los Angeles.

And that's where my anger begins. AIDS is increasingly a disease of poverty. Even Mr. Monette and Roger suffered financially because of AIDS. But the vast majority of

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BORROWED TIME (Cont'd)

people who have it just don't have a beautiful home above Sunset Boulevard in the Hollywood Hills.

The danger is that this book may be seen as the prototype of how AIDS is experienced in America. The paperback carries many reviews trumpeting the universal appeal of the story, the brilliance with which Monette describes the "plague years". Monette may not have intended this, but it feels as if he wants the reader to believe that this is the worst suffering ever caused by AIDS. There are so many who are experiencing the rigors of County Hospitals or no medical care at all that Paul's and Roger's suffering seems whiny in comparison. Mainstream readers of this book can easily forget that AIDS is mostly experienced in drab, County medical clinics and welfare offices, on the streets and in cramped, borrowed rooms. In spite of the obvious luxury that Paul and Roger live with throughout their life together, they seemed to only see the horrors around them. My teeth grated whenever Monette began to bemoan the "hotel-like" UCLA hospital rooms, or having to go to another glamorous dinner in Bel Air.

There are many parallels in this story to my own, and yet I experienced it so differently. I too, relied on the services of APLA. I too, took suramin and had the same scene as Roger when I nearly died from undetected adrenal failure. But my medical scenes happened at USC/LA County Hospital, where the uninsured go. It's curious that my adrenal failure happened a month before Roger's, across town at County Hospital, and UCLA didn't learn in that month that adrenal failure was a side effect of suramin.

I was even in one of the scenes in the book and experienced it quite differently. On pg.141 of the paperback, Monette describes that 1985 Christopher Street West Parade in West Hollywood. He and Roger watch the festivities, until they spot the AIDS contingent. An open car drives slowly by, with "boisterous people sitting out on the trunk. In the front passenger's seat sat a man with AIDS, waving gamely to the crowd on the boulevard, rather like a blessing. His lesions and his hollow look filled me with terror. I didn't want Roger to see him and turned us away: it was time to leave."

The man in the front seat was a man I had know since my own diagnosis. He had advanced KS and died about three weeks later. This was his final bid at belonging to life. The three "boisterous" people on the trunk were myself and two of the other USC suramin patients. We were wearing our "suramin AIDS-Busters" T-shirts, and we were celebrating life and gay pride, in spite of having AIDS and taking a toxic experimental drug. Monette couldn't see this. All he saw was my friend who was dying, and he couldn't even see how engaged in life he was. He turned Roger away instead. I wonder if Roger might have done better if he'd had the comradeship of the Suramin for brunch bunch every Monday over at USC, instead of the sole attention of his horrified lover at UCLA.

Part of my anger is very personal. I frankly wish I'd had a lover to lift me and carry me and tend to me as devotedly as Paul attended Roger. But maybe I survived partly because most of the time I had to get up and answer the door myself, and fix my own weight-gain drinks and clean up my own vomit. I would have loved to have a pool, a bougainvillea tree, and a lover to lie by as I recovered from suramin. But maybe I survived partly because I still had that dream to fulfill.

I had a hard time feeling sorry for Mr. Monette. I frequently had the feeling that he was crying out for me to do just that, and I resist that kind of behavior.

The first and last lines sum up my problems with the book. "I don't know if I will live to finish this." (pg1) "Putting off as long as I could the desolate waking to life alone - this calamity that is all mine, that will not end till I do." (pg342) The assumptions are all negative, afraid, doomed, isolated in his own suffering. Does he really think this calamity is "all mine", that nobody else has suffered like he has? Yes, the stark reality of facing death has a tendency to put one in that frame of mind. Believe me, I've been there. But there is a movement beyond that space that is possible. And that movement is faith, towards which Monette states much contempt throughout the book.

That is why I would not recommend this book to a newly diagnosed PWA/HIV or someone who loves them. If they have to read it, I would accompany it with a book more informed by faith: a book that demonstrates what it's like to experience AIDS while believing in God who is beyond this disease, and beyond all of our deaths. If this book is a prototype, it is a prototype of the experience of AIDS without faith. For people looking for a role model for living with AIDS, Borrowed Time is not the book.

UPCOMING SCHEDULE FOR FIELD DIRECTOR

Rev. Steve Pieters schedule of appearances for the next six months includes the following:

June 10	Morning Star MCC, Worcester, MA
June 14-17	River City MCC, Sacramento, CA
June 22-24	MCC Austin, TX
July 1	Church of Religious Science, Westwood, CA
July 15	MCC Los Angeles, CA
July 22	Christ Chapel MCC, Santa Ana, CA
Aug 16-17	AIDS Conference, DACCO, Tampa, FL
Sept 9	MCC of the Hi Desert, Palmdale, CA
Sept 15-19	AIDS National Interfaith Network Conference, Chicago, IL
Sept 21-23	MCC's in San Antonio, TX
Sept 29-30	MCC Las Vegas, NV
October 5-7	First MCC of Wichita, KS
October 12-14	MCC Toronto, Ontario, Canada
October 25-28	MCC Johnson County, KS
November 9-11	Southeast District Conference